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University of London

School of Management
Knowledge and Organizational Learning Group

Using telehealth and assistive technology to improve patient wellbeing and clinical decision making

*Public and Patients Involvement (PPI) Workshop
10 June 2016*

Final Report

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The views expressed in this publication are those of the workshop participants and the authors. Institutional affiliations are provided for purposes of identification only and do not imply endorsement of the content herein.

Acknowledgement

We would like to thank all the workshop participants for their contribution to the constructive and engaging discussions. We would also like to thank the Knowledge and Organizational Learning Group of the School of Management at Royal Holloway, University of London for funding this event.

Introduction

Researchers are becoming increasingly aware of the importance and value of involving patients, health care service practitioners and users in their work. Participants used their experience to help us understand the impact of home-based technology on health management and treatment. The workshop findings summarized in this report will be used to identify research priorities to be included in future research projects that can benefit health care service users and providers.

The workshop was organized into two breakout sessions:

- The discussion in breakout session 1 focused on the impact of telehealth on patients' wellbeing
- In breakout session 2, participants discussed how remote monitoring affects diagnosis, treatment and care decisions.

In each breakout session participants were divided into two groups and each group was assigned a set of *inspiration cards* combining the findings from domain studies. Each group had to discuss the main findings represented in the inspiration cards in relation to their own experience. Each group then presented their findings in a plenary discussion.

This report summarizes the key outcomes from the groups and plenary discussion. A more detailed summary is provided in the Appendix.

Breakout session 1 – The impact of telehealth on patients' wellbeing

Face-to-face consultations

Both groups agreed that face-to-face consultations are needed, yet, to a different extent. Group 1 emphasized the role of face-to-face consultations to establish human connection. They also argued that the need for face-to-face consultations may vary in relation to the patient's location, his/her type of condition, age, and the stability of his/her condition. In this respect, they pointed to the need for more resources for the elderly. Group 2 also agreed that face-to-face consultations are not needed all the time and that there are situations where the patient can manage his/her own health without the need of seeing a healthcare practitioner. It is in these circumstances that telehealth can be more beneficial: by empowering patients in the management of their own health, telehealth can reduce the time spent seeing a healthcare professional.

Patient self-management

Both groups agreed that patients need to be educated in the use of telehealth and in managing their own condition. The accuracy and reliability of information available online (eHealth) should also be ascertained. Patients' education allows for a correct use of the technology reducing the risk of overloading healthcare professionals with patients' alerts or requests. Both groups mentioned the importance of tailoring telehealth to an individual's personal needs. Group 1 suggested that self-management of care depends on the condition. For instance, technology may be helpful for managing a short-term condition but it may be less helpful when the condition is asymptomatic. Group 2 added that a "do-it-yourself" culture is needed, particularly, in the UK health system, where patients need to see a doctor also for minor consultations

or prescriptions. Patients should be educated to understand their symptoms and have access to a larger number of over the counter medicines without prescriptions.

Downside effects of technology

Both groups agreed that patients may perceive telehealth as over controlling. For example, Group 1 suggested that patients may be pressurized to key in data. Yet, if there is a clear benefit, patients are happy to accept technological control. Group 2 conceded that the perception of technology as either over-controlling or beneficial depends on people's mindset and how they perceive the information monitored through the system. On the one hand, some users may feel that information about their health or health activity affect their mood. On the other hand, telehealth allows you to intervene quicker, which may actually be perceived as beneficial by other users.

Social implications

Group 2 disagreed with the argument that telehealth can be alienating and a threat to independence. By contrast, the group suggested that technology can increase social interaction. Users can manage their own health through technology, which means less time at the GP and more time for their daily routines and socializing. As a result, GP has fewer consultations, less pressure and more time to spend with patients during face-to-face consultations. Under this perspective, telehealth can increase independence and quality of life. If a person is isolated and needs to see a healthcare professional to feel less lonely, it is not a telehealth issue but a societal issue.

The role of carers

In Group 2 it was suggested that telecare can release pressure on carers and allow them to take some time off. However, others suggested that some carers may feel a sense of guilt, since they do not want to leave their family members alone. Carers provide a holistic approach to the care of patients, therefore, their involvement in the provision of telecare is crucial.

Breakout session 2 – The impact of telehealth on clinical decision making

Face-to-face consultations

Both groups agreed that telehealth does not exclude face-to-face consultations. Based on the fact that 90% of diagnoses are based on face-to-face consultations, Group 1 stressed that with telehealth some important information about the patient condition can be missed. According to Group 2, face-to-face consultations are very much needed for acute patients, whereas telehealth can help with routine checks. By making them more aware of their own conditions, telehealth empowers patients to ask the right question during clinical consultations.

Healthcare professionals judgment and decision making

Both groups agreed that healthcare professionals need to base their decisions on objective data in conjunction with their own professional judgment involving a more subjective evaluation. Group 1 raised the issues of miscoding, inaccurate data and

misuse of information. All of that can lead to poor clinical decision making. Group 2 stressed the importance of putting in place the right patients assessment and set up protocol to reduce uncertainty and make sure that healthcare professionals in charge of telemonitoring know what to do when there is an alert. They also suggested that telehealth can improve communication among healthcare professionals and integration of data across healthcare organizations in support of a more efficient and effective response. Group 2 suggested that by supporting clinical decision making, telehealth can be more beneficial in preventing admissions as opposed to reducing re-admissions of acute patients. Both groups agreed that a positive effect of telehealth on hospital admissions is related to patients' education in understanding and dealing with their own medical conditions.

Social and emotional aspects of care

Group 2 argued that in a situation where clinicians are time-constrained the social and emotional aspects of care are overlooked anyway. By empowering patients in managing their own condition, telehealth could reduce the number of people visiting a clinician who may then have more time to establish an empathic relationship with their patients. It was also suggested that telemonitoring can be used to assess the social and emotional conditions of patients with a questionnaire (e.g. eating, socializing, etc.). In this case, telehealth would play a preventative role, which has to be distinguished from its other role of supporting clinical assessments and decisions through the monitoring of a patient medical condition. In addition group 1 suggested that telehealth operators can develop a rich knowledge about a patient if they have to deal with a small number of patients.

Social networks

Group 1 shared the idea that social networks are needed. They suggested that in the absence of social networks, it is the responsibility of the government to establish them (e.g. communities that support patients). By contrast, Group 2 felt that telecare allows you to live without social network. The operator can call the client directly. The direct response team of council compensate for the lack of a social network.

Performance targets

Group 1 agreed that technology has intensified the work of clinicians and healthcare professionals, because of the number of targets that they have to report. It was suggested that performance targets skew clinical practice and relationship between patient and clinician. They divert the attention onto chasing numbers instead of dealing with patients. Measurements were thought to be simplistic and not always valuable from a clinical practice perspective. Valuable targets for clinical practice would be complex, hard and costly to measure, whereas actual targets are mostly used to achieve cost-savings rather than improve clinical practice and the care of patients.

Group 2 saw a more beneficial role of targets. They thought that performance measurements can help manage a high number of patients and make more accurate decisions. In their opinion technology can help with the accomplishment of routine tasks. More time is left to longer patient consultations, which may increase people's safety.

List of studies

Breakout session 1 – Impact of telehealth on patients' wellbeing

Kelley, Helen, et al. "The clinical impact of eHealth on the self-management of diabetes: a double adoption perspective." *Journal of the Association for Information Systems* 12.3 (2011): 208.

Mort, M., Finch, T., and May, C. 2009. "Making and Unmaking Telepatients: Identity and Governance in New Health Technologies," *Science, Technology & Human Values* (34:1), pp 9-33.

Sanders, C., Rogers, A., Bowen, R., Bower, P., Hirani, S. P., Cartwright, M., Fitzpatrick, R., Knapp, M., Barlow, J., Hendy, J., Chrysanthaki, T., Bardsley, M. & Newman, S. P. (2012). Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: a qualitative study. *BMC Health Services Research*, 12(220).

Wherton, J., Sugarhood, P., Procter, R., Hinder, S., and Greenhalgh, T. 2015. "Co-production in practice: how people with assisted living needs can help design and evolve technologies and services," *Implementation Science* (10:1), p 75.

Greenhalgh, T., Wood, G.W., Bratan, T., Stramer, K. and Hinder, S. 2008. Patients' attitudes to the summary care record and HealthSpace: qualitative study. *BMJ*. 336(7656),pp.1290–1295.

Breakout session 2 – Impact of telehealth on treatment and care decisions

Crossley G, Boyle A, Vitense H, Chang Y, Mead RH; CONNECT Investigators. The CONNECT (clinical evaluation of remote notification to reduce time to clinical decision) trial: the value of wireless remote monitoring with automatic clinician alerts. *J Am Coll Cardiol*. 2011;57:1181-1189.

Mort, M., Finch, T., and May, C. 2009. "Making and Unmaking Telepatients: Identity and Governance in New Health Technologies," *Science, Technology & Human Values* (34:1), pp 9-33.

Petrakaki, Dimitra, Ela Klecun, and Tony Cornford. "Changes in healthcare professional work afforded by technology: the introduction of a national electronic patient record in an English hospital." *Organization* (2014):

Reich, Adam. "Disciplined doctors: The electronic medical record and physicians' changing relationship to medical knowledge." *Social Science & Medicine* 74.7 (2012): 1021-1028.

Seto, E., Leonard, K. J., Cafazzo, J. A., Barnsley, J., Masino, C., & Ross, H. J. (2012). Perceptions and Experiences of Heart Failure Patients and Clinicians on the Use of Mobile Phone-Based Telemonitoring. *Journal of Medical Internet Research*, 14(1): e25.

Williams, C., Wan, T.T.H. (2016). The Influence of Remote Monitoring on Clinical Decision Making: A Pilot Study. *Home Health Care Management & Practice*, 28: 86-93.

Roberts, C., Mort, M. and Milligan, C. 2012. Calling for Care: 'Disembodied' Work, Teleoperators and Older People Living at Home. *Sociology*. **46**(3),pp.490–506.

Appendix

Breakout session 1 – The impact of telehealth on patients’ wellbeing

Theme	Findings	Group 1	Group 2
Face-to-face consultation	“I prefer to go and see the doctor... If you see the doctor straight away she can just get straight to the point” (Wherton et al. 2015)	<p>Face-to-face consultation is important to establish human connection and to make patients feel they are valued.</p> <p>The need for face-to-face consultation depends on patient’s location, type of condition (chronic or not), age, stability of condition, patients’ confidence in using technology.</p> <p>More resources for the elderly.</p> <p>Health is not “numbers” – it is about being reassured by a GP/HC professional about condition (human contact, interaction).</p>	<p>Face-to-face consultations are not needed all the time. You can just get tablets and feel better.</p> <p>It takes time to get and go to a GP appointment.</p> <p>Telehealth can release time pressure.</p> <p>If a person is isolated, it is not a telehealth issue but an environmental issue, do I need to see a GP to feel less lonely?</p>
Technology helps health management	“Feedback (e.g. blood sugar level) and motivational messages (e.g. eat less salt) help keep an eye on my health” (Wherton et al. 2015)	<p>Telehealth need to be tailored to the individual’s personal needs.</p> <p>Need for resources to educate the patient in self-management.</p> <p>Self-management of care depends on the condition. For instance, technology may be helpful for managing a short-term condition but it may be less helpful when the condition is asymptomatic.</p>	<p>Compared to traditional technologies, telehealth is helpful because it gives you feedback at the right time.</p> <p>Information has to be accurate and correct, in particular, information available on the Internet</p> <p>It is important to educate the patient on how to use the technology.</p>

			<p>Professionals should not be overloaded with information – so education on how to use technology and the information from telehealth is important to avoid this.</p> <p>Some healthcare professionals do not like the idea of “delegating” patients.</p> <p>The use of technology in self-care reassures patient since they feel as if they are looked after.</p>
Technology is over-controlling	<p>“I want to control my diabetes. If I fancy a bit of ice-cream, I’m going to have it because I want to feel good. It’s not good feeling guilty after eating. But I won’t overdo things, and do things in moderation” (Wherton et al. 2015)</p>	<p>Patient is forced to input data (pressurized).</p> <p>Too much nagging.</p> <p>If there is a clear benefit patients are happy to accept technological control.</p>	<p>Perception of technology as either “over-controlling” or beneficial depends on people’s mindset, how they perceive the information.</p> <p>Telehealth allows you to intervene quicker, which may be perceived by individual as over-controlling, but it is actually beneficial.</p> <p>Information about health or health activity can affect user mood.</p>
Patient self-management	<p>The use of learning resources on the Web improves patients’ self-care. Patients develop specific and implicit knowledge about their condition and what affects their health outcomes. (Kelley et al. 2011)</p>	<p>Self-care learning resources and websites need to be accredited by a central authority.</p> <p>Patients need to be educated in order to evaluate health information they receive.</p>	<p>Patient should receive feedback at the right time.</p> <p>Feedback should be accurate/correct.</p> <p>Need to educate patients about the technology (how it should be used to better manage their health; what are the advantages?).</p>

Patient self-efficacy	Technically less-proficient patients may be able to access eHealth systems, but they need the clinics to foster patients' self-efficacy toward system use and not technical proficiency per se (Kelley et al. 2012).		Technology provides self-empowerment, an improved understanding of one's condition.
The role of carers	Patients are concerned that telecare systems might not include informal carers and that new systems might not be able to do justice to the very complex role that informal carers perform in practice (Roberts, Mort and Milligan 2012).		<p>Telecare can release pressure on carers and allow them to take some time off.</p> <p>Patients are the "authority". If they want telecare, carers will have to abide by their decision.</p> <p>Some carers may feel a sense of guilt, since they do not want to leave their family members alone.</p> <p>Carers provide a holistic approach to the care of patients.</p> <p>There is an element of risk – it is important to identify who is the first in the line to call.</p>
Technology is alienating	Patients reject to adopt telehealth because they find it difficult to engage with technology and are concerned about its alienating consequences (Sanders et al. 2012).		<p>Technology increases social interaction. By managing their health with technology, users spend less time at the GP and have more time for their daily routines and to socialize.</p> <p>As a result, GP has fewer but longer face-to-face consultations.</p>

Threat to independence	Patients see telecare as a threat to their independence and as being expressive of ill health. Telecare was for them an indication that the patient needs – but lacks - constant support (Sanders et al. 2012).		Telecare is not a threat to independence. By contrast it increases quality of life, independence and freedom of movement. It gives GP a more accurate picture of patients’ behaviour thereby making GP consultation more efficient while releasing pressure on the health service.
Self-monitoring	Patients are reluctant to conduct self-monitoring of their health through telecare and prefer to rely on healthcare professionals. They reject the assumed responsibility they are supposed to be taking (Sanders et al. 2012).		Health system in the UK is patriarchal: “we will do it for you”. Instead there should be more of a “do-it-yourself” culture. Patients should be educated to understand their symptoms and have access to a larger number of over the counter medicines without prescriptions.
Health anxiety	Access to their own medical data makes patients more hypochondriac and constantly concerned about their health (Greenhalgh et al. 2008).		Varies across individuals. Health anxiety through technology increases in subjects that are already hypochondriac. Users should be trained to use the technology according to their personality.

Breakout session 2 – The impact of telehealth on clinical decision making

Theme	Findings	Group 1	Group 2
Face-to-face consultations	Without face-to-face interaction, clinical staff miss important information that is exchanged through cues. Face-to-face contact between patient and clinician should support any move to telehealthcare (Mort, Finch and May 2009).	<p>With telehealth, some important information can be missed (e.g. hygiene).</p> <p>90% of diagnosis are based on face-to-face consultations and 10% on tests.</p> <p>Face-to-face consultations are important, especially for first consultations.</p> <p>For chronic conditions, some form of telemonitoring can take place.</p> <p>Without face-to-face consultations some important information is missed for instance smoking, personal hygiene.</p>	<p>Technology can help with routine checks.</p> <p>Telehealth does not exclude face-to-face.</p> <p>Telehealth is not a replacement of acute care.</p> <p>Telehealth increases patients' awareness on their own conditions, it allows patients to ask right question during clinical consultations.</p> <p>Sometimes patients are overloaded with information about care options that makes them disadvantaged and confused.</p>
Uncertainty in clinical decisions	There are circumstances where nurses are not knowledgeable about patients' information monitored through the system. This may result into uncertainty and delay clinical decisions (Pettrakaki et al. 2014).		<p>Uncertainty occurs because of errors in the patients assessment and setup protocol.</p> <p>Telehealth can support decision making by enabling communication between mental and physical health services.</p> <p>Effective response depends on easier communication among healthcare professionals, and data integration.</p>

<p>Healthcare professionals judgment</p>	<p>Technology limits healthcare professionals' judgment: their work is less reliant on their abstract knowledge and experience and more dependent on the information stored in the system (Pettrakaki et al. 2014).</p>	<p>Clinical experience should go together with quantitative information. Data and judgment should be used in unison (statistics + qualitative information obtained in face-to-face consultations). Quality of data is important: miscoding can lead to poor clinical decision making, data can be misused and also be inaccurate, which may increase risk.</p>	<p>Objective information extrapolated from the system should be used in conjunction with subjective information. The importance of "abstract knowledge" relates to the consideration of patients as persons rather than numbers.</p>
<p>Social and emotional aspects of care</p>	<p>"Technology [...] may reduce physicians' appreciation of those social and emotional aspects of care that are less quantifiable but equally important to patient well-being" (Reich 2012).</p>		<p>Two aspects of care: one is that focuses on the holistic well-being of the individual and, one that is more practical concerning the need for medication. UK healthcare system is different from US: health insurance companies want hospitals to embrace telehealth because they want them to do more preventative care which is cheaper. In a situation where most GPs are time-constrained there is not much dedication to the social and emotional aspects of care anyway. Two roles of telehealth: Prevent – in this case you use telehealth to assess the social and emotional conditions of patients</p>

			with a questionnaire (e.g. eating, socializing, etc.). Management of patients' condition – social and emotional aspects are less relevant, questionnaire focused on medical condition.
Social networks	Telecare relies on social networks. Ambiguities arise when alarms are triggered. Operators need to call family, friends, neighbours, etc. to understand what is happening in the client's home (Roberts, Mort and Milligan 2012).	Social networks are needed and in the absence of social networks, it is the responsibility of the government to establish them (e.g. communities that support patients).	Telecare allows you to live without social network. Operator can call client directly. Direct response team of council compensate for lack of social network.
Cumulative knowledge	Telecare operators gradually accumulate knowledge of a client and use it to "talk him/her into" doing something and reassure him/her about a situation. In this way they create a kind of "virtual co-presence" (Roberts, Mort and Milligan 2012).	Rich knowledge of operator depends on number of patients. With a small number of patients telecare can work more effectively. Face-to-face consultations need to accompany telecare.	Operators know frequent callers (Implicit/tacit knowledge). Operators' knowledge is reassuring for the client.
Performance targets	Telemedicine systems have a quantitative/output orientation that encourages the introduction of targets (e.g. consultations/day). Clinical staff may be put under pressure to meet targets, compromising safety (Roberts, Mort and Milligan 2012).	Performance targets may be detrimental to clinical priorities. Intensified work of clinicians and HC professionals, because of no. of targets that they have to report. Technology has intensified the use of targets. Performance targets skew clinical practice and relationship between	A problem exists if you do not have enough resources to keep the system working efficiently (e.g. not enough broadband to deliver my teleconsultations). Under these conditions meeting targets may be seen as a challenge. Technology can help with routine tasks, freeing up time, which increases people's safety –e.g.

		<p>patient and clinician. They divert attention onto chasing numbers instead of dealing with patients.</p> <p>Measurements are simplistic, not always valuable from a clinical practice perspective.</p> <p>Valuable targets for clinical practice are complex, hard and costly to measure.</p> <p>Technology and targets are often misused. They are mostly used to achieve cost-savings rather than improve clinical practice and the care of patients.</p> <p>Promote shortcuts and workarounds.</p>	<p>longer interactions can be safer for patients.</p> <p>Performance measurements help manage high number of patients and make more accurate decisions.</p>
<p>Remote monitoring impact on clinical decision making</p>	<p>Remote monitoring decreased the time to clinical decision making and decreased the length of hospital stay, but there were no significant differences in hospital readmissions (Crossley et al. 2011).</p>		<p>Telehealth is long-term investment – you should not expect short-term returns.</p> <p>Telehealth can't stop the re-admission of acute patients.</p> <p>Its function should be preventative and target patients before they enter an acute stage. In this way it reduces admissions and stops people from going into hospitals.</p> <p>It is important to distinguish between social admissions (I go to A&E because I am alone) vs. clinical admissions.</p>

<p>Meaningful use of information</p>	<p>The value of remote monitoring was obviated by lack of consideration of the information in the system as evidenced by inadequate implementation of physician contact, patient education, or other forms of treatment to deter hospitalizations (Williams and Wan 2016).</p>	<p>Patient is poorly educated Meaningful use of information is dependent upon patients' use; physicians' adoption of technology and financial strength and resources to implement technology.</p>	<p>Patient education is important, the whole purpose of telehealth is to empower the patient. Patients may end up knowing their medical condition better than their clinician. The use of data by clinicians is important.</p>
<p>Nurse should manage alerts</p>	<p>“(Managing alerts) is suited for a nurse practitioner. Most of the issues you're dealing with are straightforward. They really probe into what a patient has been up to and they scratch below the surface more” (Seto et al. 2012).</p>		<p>Because vital signs are transferred directly to nurse, patient can't mislead by giving inaccurate information. You use telehealth for conditions that are not acute or extreme, thereby you do not need a specialist clinical knowledge.</p>